Collaborative Improvement and Innovation Network (CoIIN) to Advance Care for Children with Medical Complexity (CMC):

Family Focus Group Themes

Analysis of family focus group data resulted in the emergence of several themes that were critically important to supporting **1)** child quality of life and **2)** family well-being. The following themes describe the factors that contribute to these two key outcomes.

THEME
1

Types of Support Needed

Families identified three main types of support as necessary to ensuring child and family well-being: understanding and inclusion, emotional support, and physical support systems.

> *"My connections with other parents have led me to this whole world of inclusive education that I just really feel strongly about. He got to do adaptive ski a couple weeks ago because I found out about an opportunity through other parents. They're just so many things that I've learned from other parents that have helped me."*

THEME
2

The Care Team

Families reported ways in which their care teams both exacerbated and addressed unmet needs for families.

> *"They're very open to hearing me, and listening to me, and understanding me. They always give me the option...and we discuss the side effects... Then if I say, I don't think it's worth the risk…they listen to me."*

THEME
3

Improve Care Coordination

Families cited several important aspects of care coordination that are necessary to improving child and family quality of life: provider communication, dedicated care coordinators, and accessible medical information.

> *"There is no coordination among the different systems. So, I as the parent end up being the patient navigator."*

THEME
4

Focus on the Whole Family

Focus group participants described the importance of families and clinicians partnering with one another to ensure the well-being of the entire family unit.

> *"To support the well-being and personal emotional health of myself, my husband, and the other three children...it can be really emotionally exhausting."*

THEME
5

Care Accessibility

Families expressed the importance of appointment coordination and increased appointment availability to their quality of life.

> *"[I] can never get his appointments lined up. So, he might miss two or three days of school every week."*

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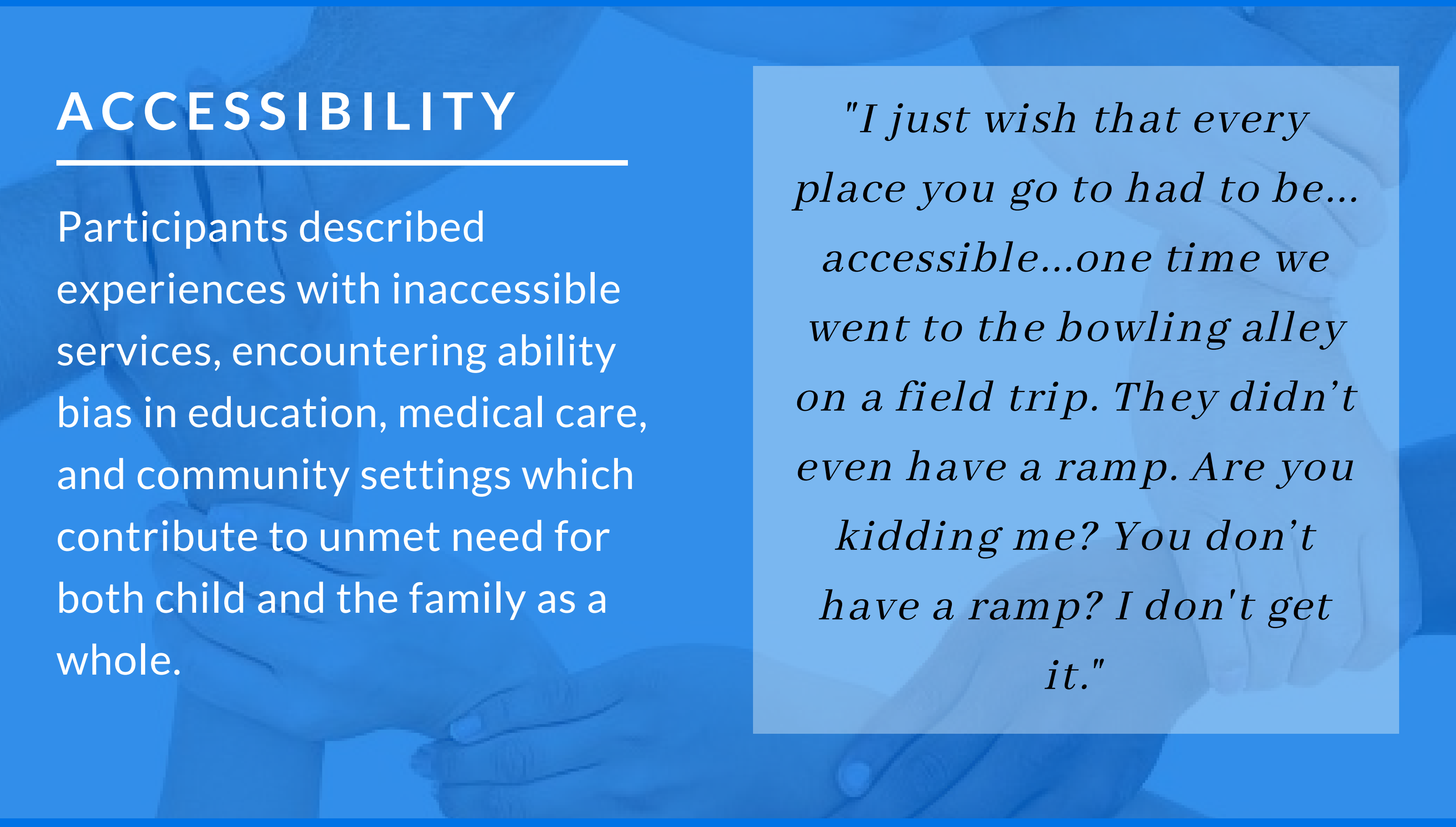
TYPES OF SUPPORT NEEDED

Having family, institutional and community support systems is critical to minimizing unmet caregiving, accessibility, and emotional needs for children and youth with medical complexity and their families.

COMMUNITY SUPPORT

How can society help meet the needs of children with medical complexity if it doesn't understand who they are and what they need? Focus group participants were unanimous in stating that there is a fundamental and societal lack of understanding of CMC across the United States.

> *"When you go out in the community, and people stare...people don't understand, I just sit in my bubble. And I feel like I'm going through this by myself and no one understands."*



ACCESSIBILITY

Participants described experiences with inaccessible services, encountering ability bias in education, medical care, and community settings which contribute to unmet need for both child and the family as a whole.

> *"I just wish that every place you go to had to be... accessible...one time we went to the bowling alley on a field trip. They didn't even have a ramp. Are you kidding me? You don't have a ramp? I don't get it."*

EMOTIONAL AND PEER SUPPORT

Families cited a lack of emotional support and understanding from peers, family members, and the community at large, which contributed to feelings of isolation and made it challenging to meet the needs of their child.

> *"I just, I don't have a support system. I've tried to reach out to other special needs parents and a lot of them are struggling and they don't really [have the time]. I feel like I'm alone..."*

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THE CARE TEAM AND UNMET NEEDS

Focus group participants spoke about how their child's care team was addressing unmet needs.

COMMUNICATION

Parents noted a lack of communication between providers:

"My son's pediatrician will have an idea of what she wants to do and then his specialist will have a different idea...they need to communicate better."

ABOVE AND BEYOND

Providers formed close relationships with families of children with medical complexities:

"They'll send a message through just checking in...somebody's actually caring here. I'm not just the next number on their appointment book."

PARENTS ARE PART OF THE CARE TEAM

Empowering the voice of children with medical complexities and family members:

"Then if I say, I don't think it's worth the risk to ruin her day over maybe getting two extra days without a seizure...then they listen to me."

TRANSITIONING TO ADULT CARE

Transitioning to adult care at age 18:

"If a physician could say 'Hey, you know, this is gonna happen, this is what you can do,' that would be helpful, instead of having to try and dig and find that information."

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CMC COIIN FAMILY FOCUS GROUPS

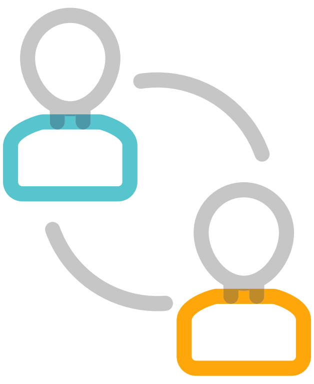
NEED FOR IMPROVED CARE COORDINATION

PHYSICIAN COORDINATION

Focus group participants frequently described a disconnection between providers that created additional challenges for accessing timely and coordinated care.

FOCUS GROUP QUOTE

“The very first thing they could do is talk to each other because they don't. There is no coordination among the different systems. So, I as the parent end up being the patient navigator...”

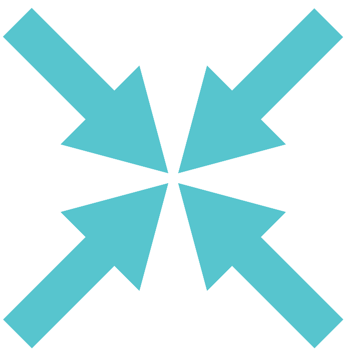


DESIGNATED CARE COORDINATOR

Participants mentioned how having a dedicated care coordinator proved helpful to them. Patient navigators, case workers or managers, social workers, and others were thought to be beneficial to CMC families in navigating a fragmented healthcare delivery system.

FOCUS GROUP QUOTE

"A coordinator needs to be a person that advocates for the families, but also coordinates all that information from SSI, Medicaid, specialty care with the hospital, how to get diapers, what are the formula options for your child, all of these things.”



CENTRALIZED MEDICAL INFORMATION

Focus group participants suggested having their child's medical information in a single, centralized place. This would save them time in calling multiple providers to ensure that their child's information was accessible, and make it easier for them to review all important information.

FOCUS GROUP QUOTE

"You get tidbits here, there, everywhere. For example, we had mentioned we were buying diapers for years. And she was like, ‘Why aren't y'all getting on [program name]?’ And we didn’t know we could. There's just no consolidation of information...having that all [the resources] in one place with our medical information would be so nice."

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FAMILY WELL-BEING

COMMON BARRIERS AND STRATEGIES FOR ACHIEVING SUCCESS

Parents of children with medical complexity cited several common issues that arose as the result of being the primary caregiver for a child that requires full time care and support. These included physical, emotional, and financial problems, as well as concerns about making sure all members of the family felt included and loved. Strategies helpful in addressing these issues included:

COUNSELING AND PERSONAL TIME

Families discussed two primary mechanisms, counseling and adults-only time, that helped parents to find personal time and specifically address the needs they had.

"I just recently started seeing a counselor...not something that is easy to do with scheduling and trying to figure out coordinating care and all of that fun stuff, but that has been the best decision that I've ever made."

EMPLOYMENT CONSIDERATIONS

Families described the challenges they face in balancing their employment with keeping up with the needs of their child. Several parents discussed how they required flexibility in their jobs because of the unpredictable nature of their child's complex care needs.

"I do network marketing now because it's the only job that I can do where I can stay at home. I can still earn an income, but I can drop everything when I need to, to rush to pick up a kid that's throwing up at school."

STRUCTURAL ADJUSTMENTS WITHIN THE HOME

Families asserted that caring for children with medical complexity is more than just about the complex care needs that their children face. There were fundamental personal, life, and family changes that needed to be made, as well as structural changes to their homes.

"We really kind of have a set structure about how we're going to handle holidays and time spent with extended family... we've really set some boundaries around how much time we spend, what we do and things like that."

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Accessibility of Services

Efficient Scheduling

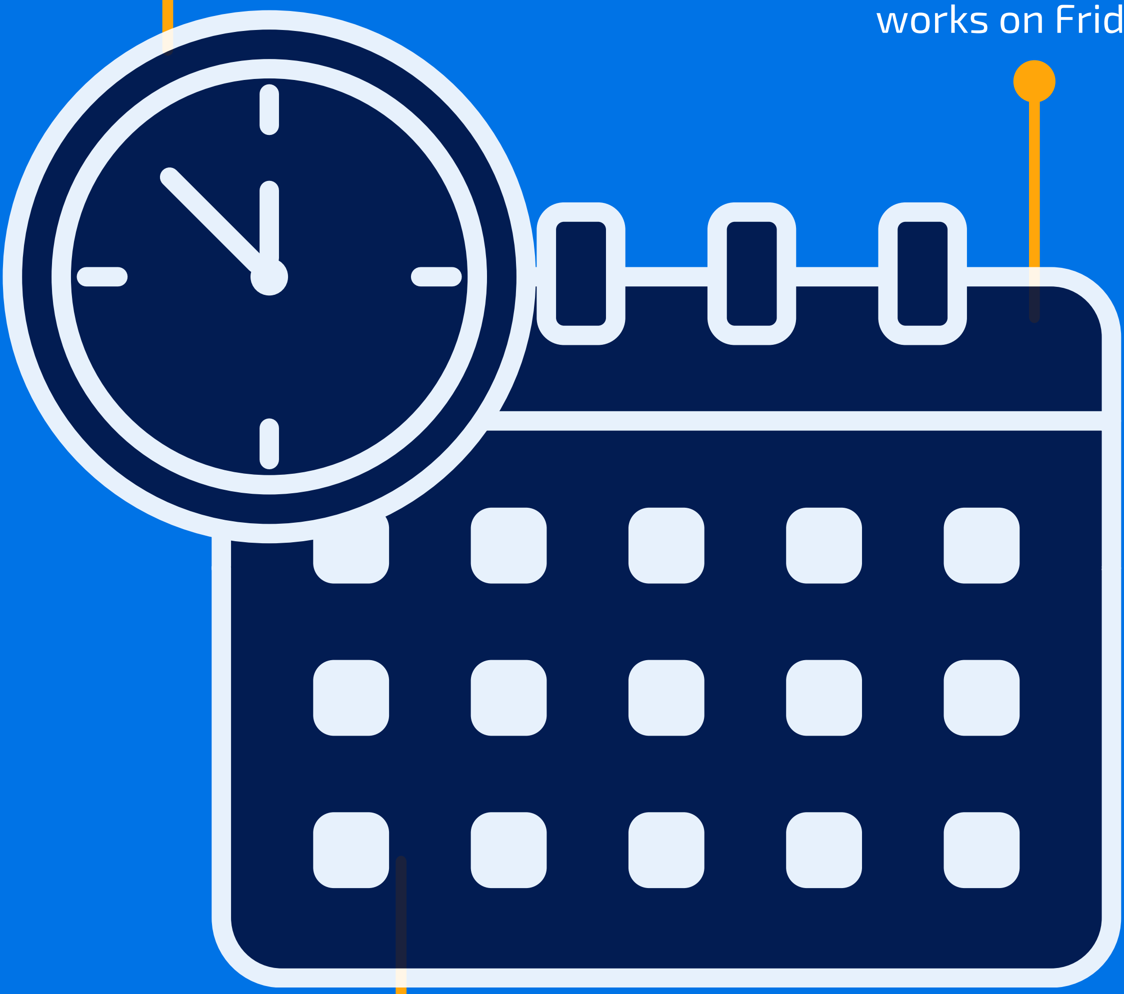
Focus group participants discussed how accessibility of services is important to their quality of life. Families cited the importance of appointment coordination and more appointment options as key to ensuring that their child is achieving optimal health and well-being.

Appointment Coordination

Families discussed challenges related to scheduling conflicts, and desires for greater coordination between appointments during the week.

"[the hospital] is two hours away, at least a two-hour drive for us, being able to have somebody try to coordinate appointments is huge"

"It's tough because providers may only work two days a week. I know for my daughter for the cerebral palsy clinic and orthopedic clinic are only on Wednesdays. But then the pulmonologist only works on Friday."



"I wish that physical therapy and occupational therapy and other therapies were available on the weekend or by evenings."

More Appointment Options

Families also described challenges related to appointment availability during the week. Several parents expressed a desire for more appointment times outside of typical business hours.

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